Running title: Online evidence-based module on DCD

Title: Using an evidence-based online module to improve parents' ability to manage their child with Developmental Coordination Disorder

Keywords

Motor Skills Disorders, Translational Medical Research, Rehabilitation, Pediatrics, Family

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Acknowledgement

The first author was a post-doctoral fellow funded through the Canadian Institutes of Health Research (CIHR), the Fonds de la Recherche du Québec – Santé (FRQS) and the Canadian Child Health Clinician Scientist Program (CCHCSP) - Career Enhancement Program at the time of the study. The Strauss Foundation at McGill University provided financial support for this project. Funders were not involved in study design, data collection, data analysis, manuscript preparation and /or publication decisions. The authors state that they have no interests that might be perceived as posing a conflict or bias.

We are grateful to our partner organizations, namely the *Centre de Réadaptation Estrie*, the *Institut de Réadaptation en Défience Physique de Québec* and the *Association Québécoise pour les Enfants Dyspraxiques*. We are also grateful to the health professionals and parents who participated in this study, and to our other colleagues, including Robin Gaines, Audette Sylvestre, Lisa Rivard, France Léger, Marie-Ève Langevin and Marie-Chantal Rhéaume.

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Abstract : 246 words

Manuscript : 4136 words

References : 42

Tables : 4

Using an evidence-based online module to improve parents' ability to support their child with Developmental Coordination Disorder

Abstract

Background : Developmental coordination disorder (DCD) is a prevalent neurodevelopmental disorder. Best practices include raising parents' awareness and building capacity but few interventions incorporating these best practices are documented.

Objective : To examine whether an evidence-based online module can increase the perceived knowledge and skills of parents of children with DCD, and lead to behavioral changes when managing their child's health condition.

Methods : A mixed-methods, before-after design guided by the theory of planned behavior was employed. Data about the knowledge, skills and behaviors of parents of children with DCD were collected using questionnaires prior to completing the module, immediately after, and three months later. Paired T-tests, sensitivity analyses and thematic analyses were performed on data as appropriate.

Results: One hundred-sixteen, 81 and 58 participants respectively completed the three questionnaires. For knowledge and skills, post- and follow-up scores were significantly higher than baseline scores ($p<0.01$). Fifty-two (64%) participants reported an intention to change behavior post-intervention and 29 (50%) participants had tried recommended strategies at follow-up. Three themes emerged to describe parents' behavioral change: sharing information, trialing strategies and changing attitudes. Factors influencing parents' ability to implement these behavioral changes included clear recommendations, time, and 'right' attitude. Perceived outcomes associated with the parental behavioral changes involved improvement in well-being for the children at school, at home, and for the family as a whole.

Conclusions : The online module increased parents' self-reported knowledge and skills in DCD

management. Future research should explore its impacts on children's long-term outcomes.

Introduction

Providing information to families is a key strategy to effectively manage many childhood chronic conditions, including Developmental Coordination Disorder (DCD)[1,2]. DCD is a prevalent (5-6%) health condition that impacts on children's everyday functioning in self-care (e.g., dressing), academic tasks (e.g., handwriting) and motor activities (e.g., riding a bicycle)[3,4]. Without appropriate support, these children are at increased risk of depression, anxiety, decreased self-esteem and physical fitness, and childhood obesity[5,6]. Despite the fact there is a consensus on the importance of providing information to families to raise their awareness about the condition and build their capacity to manage the health condition[1,2], parents of children with DCD often report having a lack of information [7], which echoes parental reports for other childhood disability conditions [8,9].

Relatively few interventions have been developed specifically to increase parents' awareness of, and capacity to manage, DCD. Information sharing between clinicians and parents is often part of service delivery models, such as the Partnering for Change model, where occupational therapists share information and build capacity in teachers and parents[10]. Likewise, some rehabilitation centers provide parents with information sessions to help them better understand DCD[11]. However, in such interventions, sharing information is perceived to be part of the general responsibilities of therapists and the outcomes related specifically to sharing information with parents are not documented. Physicians and rehabilitation professionals can, however, use specific interventions to increase parents' awareness of DCD and build their capacity to manage the health condition. These professionals are ideally positioned not only to provide information about DCD, but also to recognize and facilitate its diagnosis as families often consult with them about coordination difficulties, failure to develop motor skills or problematic behaviors[12,13].

Nevertheless, busy clinicians do not always take/have the time to discuss these issues thoroughly with parents and to provide them with all the information they need.

Many families rely on the Internet to look for information and understand their health issues[14,15], especially in relation to chronic conditions[15]. The quality of the information found on the internet can be highly variable, and therefore it has been suggested that health professionals should be proactive in directing families to high quality, evidence-based sources[16], and provide feedback on information their patients discover on the internet[17,18]. In the DCD field, very little research has been done to investigate how the internet could be used to increase DCD awareness and build capacity. In one study, a virtual platform with suggested readings was provided to parents and a clinician was available to speak with family by phone. Parents were satisfied with the intervention but no other outcomes were evaluated [19]. Likewise, a DCD online module was developed and posted on a childhood disability research center website; preliminary results highlighted improvement in self-perceived knowledge and skills but no information was available with regards to change in behaviors[20]. In childhood disability in general, a systematic review of internet-based self-management interventions for youth with chronic health conditions found conflicting evidence regarding the interventions' ability to improve disease-specific knowledge and quality of life[21]. Authors of this review concluded that we are just beginning to understand how internet-based resources could improve outcomes for children with disabilities.

This study investigated whether an evidence-based online module would increase parents' perceived knowledge of, and skills in, managing their child's DCD. We hypothesized that the module would have an immediate and a short-term impact on self-perceived knowledge and skills, and thus knowledge and skills scores would be higher immediately after viewing the

module and three months later compared to scores before viewing the module. Given that the online module proposed practical strategies, we also intended to document participants' self-reported behavioral changes at three months with regards to how they managed their child's DCD. We also aimed to explore the outcomes of the behavior change, as well as the factors influencing parents' ability to change behavior.

Methods

This project was approved by the Rehabilitation Interdisciplinary Research Center and the Hamilton Integrated Ethics Research Board.

Design

This knowledge transfer (KT) intervention study used a pre-post mixed methods design with a collaborative approach guided by the Knowledge-To-Action (KTA) model[22] to examine the uptake of evidence by parents in the management of DCD. Specifically, this study addressed one of the last phases of the KTA cycle - evaluation of the outcomes. The Theory of Planned Behavior[23] was used to guide the data collection. Core concepts of this theory stipulate that attitude, subjective norms and perceived behavioral control influence behavioral intention, which in turn influences behavior. More specifically, we used the extent of DCD knowledge to document attitude (because beliefs are related to the understanding of the disability) and self-perceived skills to manage DCD to document perceived behavioral control. Data about beliefs and self-perceived skills were collected before, immediately after and three months following viewing the module. In the post-intervention questionnaire, we also included questions to document changes participants wished to implement with regards to how they manage their child's DCD (*their behavioral intentions)*. In the three months follow up questionnaire, questions documented changes reported following completion of the module (the *behavior changes*). Interpretation of results was also informed by the Theory of Planned Behavior[23] to explore how behavioral changes, outcomes and factors influencing changes related to participants' attitudes, subjective norms and perceived behavioral control.

Intervention

The evidence-based DCD online module was a French translation and Québec adaptation of a self-help tool developed by international experts at *CanChild* that had been piloted successfully in Ontario[20] (although both are Canadian provinces, English is the spoken language in Ontario while French is the spoken language in Québec. Moreover, health care systems are of provincial jurisdiction and thus services differed across provinces). Adaptations to the module were minor, as an advisory committee composed of clinicians and parents perceived that the information was relevant for individuals in Québec. Modifications included providing information about the services in Québec (rather than in Ontario) and adding resources written in French (instead of in English). The online module takes about 1-2 hours to complete and includes information about: 1) Characteristics of DCD, 2) DCD at school, 3) DCD at home, 4) DCD during play time, 5) Strategies to manage DCD, and 6) Spread the Word - which contains additional resources to learn more about DCD. The module builds on effective knowledge translation strategies including the use of multimodal interactive components[24–28] and includes a case scenario, videos, experiential exercises, PDF resources, and links to other websites. The French DCD online module was posted on *CanChild's* website (http://elearning.canchild.ca/dcd_workshop/fr/index.html) and was freely accessible to visitors.

Setting and Participants

A convenience sampling method was used. Parents who self-reported having a child with a confirmed or suspected diagnosis of DCD, spoke French and had never seen the DCD online module before were included in the study. Participants were recruited between November 2014 and February 2015 through three different strategies: 1) a pop-up ad presenting the study opened when visitors came to the DCD website; 2) health professionals from two Quebec rehabilitation

centers offering services to children with DCD invited their clients. Pamphlets about the study were also posted in the waiting room and on their websites; 3) the Québec parent association for children with DCD invited parents and disseminated information about the study in newspapers, and on their website and Facebook page. Parents also used social media to share information. All of these recruitment strategies referred potential participants to an electronic consent posted on Survey Monkey®. Following electronic consent, participants were automatically referred to the first of three questionnaires.

Outcome Measures and Analysis

The baseline, post- and follow-up questionnaires included closed and open-ended questions to document self-reported: knowledge about DCD, skills in managing DCD, intention to change how they managed DCD, behavioral changes in managing DCD three months after completing the module, perceived outcomes of these changes and factors influencing their ability to change. Although some questions varied across questionnaires, the same 8 and 11 items respectively relating to knowledge and skills were included in all questionnaires to document change over time (see Table 3). These questions used a 7-point Likert scale (ranging from 1=not at all to 7=very well). All questionnaires were based on those used in previous DCD studies[20,29] and were reviewed by health professionals and parents. Overall, the baseline-intervention questionnaire contained 40 items (37 close-ended questions and 3 open-ended), including background information (e.g., children's age, services received); the post-intervention questionnaire contained 32 items (28 close-ended questions and 4 open-ended), and the follow-up questionnaire included 42 items (33 close-ended questions and 9 open-ended). Questions to document behavioral intention were included in the post-questionnaire only (e.g., following this online workshop, do you intend to change something about how you manage your child with DCD? Please explain).

Questions to document behavioral changes (e.g., please provide examples of things you changed, or tried to change), factors influencing behavioral changes (e.g., please describe anything that could have influenced, positively or negatively, your ability to implement desired changes) and perceived outcomes associated with these changes (e.g., please describe the impact of these changes on your child, your family and your environment) were included in the follow-up questionnaire only.

Questionnaires were posted on Survey Monkey®. Following completion of the baseline questionnaire, participants were directed to the online module. Upon completion of the module, a pop-up window appeared at the top of the screen inviting participants to respond to the post-intervention questionnaire. If needed, a research assistant sent an email reminder one week after completion. Three months later, participants received an email with a direct link to the follow-up questionnaire.

Analysis

Descriptive statistics (means, standard deviations and frequencies) were calculated as appropriate for each close-ended item. To eliminate potential sources of bias between lost-to-follow up participants and participants, paired t-tests and chi-square tests were performed, as appropriate, on key demographic characteristics (age, gender and education level of the child; the responder's place of residence and relation to the child; and whether the child received health and rehabilitation services or has received an intervention plan in the past year) and on self-reported knowledge and skills scores. For participants, total mean scores were computed for DCD knowledge and DCD skills, and paired t-tests were performed using SPSS 22 to evaluate significant changes between the post and follow-up scores versus baseline scores. In order to

address the attrition rate, a last observation carried forward (LOCF) sensitivity analysis was carried out by assigning baseline scores to post- and follow-up scores for participants who did not complete the post and follow-up questionnaires (and by assigning post scores to follow-up scores for participants who did not complete the follow-up questionnaire).

Thematic analysis of responses to open-ended questions was conducted followed Braun and Clarke's principles[30]. Specifically, two co-authors (CG and VF) generated initial codes and met with a third reviewer (CC) to identify themes and achieve consensus. Qualitative information and quotes (translated from French) were interpreted based on the Theory of Planned Behavior[23] to illustrate key themes around management of DCD. Following a mixed-methods study approach, qualitative data was used to provide a greater understanding of the descriptive statistics with regards to self-perceived changes in behaviors, and to explore outcomes and factors influencing changes.

Results

One hundred and sixteen (116) parents consented to participate and completed the baseline questionnaire; 81 completed the post-questionnaire and 58 completed all three questionnaires, for an overall attrition rate of 50%. The context and implications of this attrition rate are addressed in the Discussion. There were no significant differences found in baseline knowledge and skills, nor in key socio-demographic characteristics between those who completed one, two or all three questionnaires, as demonstrated in Table 1.

Table 1 presents the socio-demographic details of the participants and Table 2 presents the services participants reported receiving prior to the study.

[Insert Table 1 and Table 2 about here]

Impact of the DCD online module on parental knowledge and skills

All post and follow-up knowledge and skills items' scores, as well as total scores, were higher than the baseline scores (see Table 3). Table 3 also shown there was as significant difference between post and baseline scores both for knowledge [$t(80)= -7.03$, $p<0.01$] and for skills [$t(80)= -8.71$, $p<0.01$]. The same was true at follow-up (knowledge [$t(57)= -7.85$, $p<0.0001$]; skills [$t(57)= -7.70$, $p<0.0001$]). These differences remained significant ($p<0.01$) when LOCF sensibility analyses were undertaken with post-intervention knowledge scores [(Mean=5.85, Standard Deviation=1.10) vs. (M=5.21, SD=1.17); $t(115)= -6.46$, $p<0.0001$] and follow-up scores [(M=5.65, SD=1.17) vs. (M=5.21, SD=1.17); $t(115)= -6.35$, $p<0.0001$]; as well as post-

intervention skills scores [(M=5.14, SD=1.29) vs. (M=4.35, SD=1.21); t(115)= -7.70, p<0.0001] and follow-up scores [(M=4.87, SD=1.33) vs. (M=4.35, SD=1.21); t(115)= -6.27, p<0.0001].

[Insert Table 3 about here]

Parents' intention to change how they manage DCD

Immediately after completing the online module, most (n=52, (64%)) participants reported intention to change something about how they managed their child with DCD. Three principal themes emerged: understanding DCD better; changing attitudes (e.g., reducing expectations) and trialing strategies (e.g., breaking down the task). Parents wished to understand DCD but also wanted their child and the adults around him or her to understand the condition. They planned strategies to share this information and to help others understand better. Participants also mentioned the importance of having access to the information contained on this website soon after diagnosis:

> *If it was day 1 following diagnosis, the website contains everything I would have liked to know and what I have learned from different sources. This is an excellent source of information.*

> *Talking more with my child about his difficulties and the underlying causes (not only talking about his difficulties.)*

Parents' behavioral changes regarding how they manage DCD

Table 4 presents findings from close-ended questions about behaviors related to sharing information, seeking information and trialing strategies to better manage DCD.

[Insert Table 4 about here]

In the qualitative analysis, sharing information and trialing strategies also emerged as themes reported by participants, along with changing attitudes. Parents shared information with different people, including the child's physician. Most parents shared general information about DCD and the website (e.g., the internet link) but some shared specific resources, such as information about how to diagnose DCD (with physicians), specific videos, PDFs or experiential exercises (e.g., with extended family). The goal for parents was to raise awareness about DCD and to have others understand the struggles faced by their children in completing simple motor tasks, such as writing and using scissors.

Parents reported having tried different strategies recommended on the online module such as adapting activities (e.g., choosing clothes that are easier to put on) and introducing adapted tools and technology (e.g., using computers to write). Some also reported having made a life-changing decision, such as modifying their work hours. One parent even reported moving in order to change their child's school.

Parents reported changing their attitudes toward their child, trying to be more patient and modifying their expectations ("*he won't be an athlete*"). Parents reported focusing more on supporting their child (rather than repeating instructions) and paying more attention to how the child's difficulties impact on confidence.

Outcomes associated with behavioral changes

The outcomes associated with these behavioral changes were closely interwoven with a greater understanding of DCD and specific to the change implemented, either at school or within the family, and lead to greater well-being for the child.

At school, better understanding of DCD by educators led to more adaptive strategies for the child with DCD, in class and for homework:

> *When exercises are done in big group, [the teacher] doesn't ask him to write and listen at the same time. I have the feeling she doesn't ask him as often as before to copy what is on the blackboard.*

> *We now understand his difficulties better, what he says; we don't think anymore he is wasting his time, we know he is simply tired at the end of the day. He doesn't have the energy to write during homework, so we do it for him. We use a writing board and don't focus on the writing but on the content of the sentence and the spelling.*

At the family level, better understanding of DCD by parents and the extended family led to modifications to families' daily routines and perceptions of their child, and improved quality of life.

> *Our family stopped saying "he is only clumsy, don't worry" or "he simply has no more energy"; they are more receptive and understand better his errors or his behaviors. They are more patient.*

Everybody is happier and less stressed. DCD will always be there but we need to adapt as a family if we want to be happy.

Children with DCD appeared to benefit from these adaptations, at school and at home, and increased their well-being and self-esteem:

Academic results are spectacular, very nice school report, better self-esteem; he is also less reluctant to try new activities.

Factors influencing behavioral changes

Overall, participants reported in the follow-up questionnaire that the information contained in the online module responded to their child's needs (M=5.7/7; SD= 1.2), covered what they believe is important for their child (M=5.8/7; SD=1.2) and contained practical recommendations (M=5.9/7; SD=1.2). When asked to rate factors influencing behavioral changes, participants felt that they had the necessary time and resources to implement the strategies recommended in the online module (M=4.9/7; SD=1.4) and that adults in the child's environment were open to implementing new strategies (M=4.8/7; SD=1.4). However, only half of the participants (n=29; 50%) reported having tried to implement new strategies. They mentioned having been able to only partially implement the strategies they intended to (M=4.8/7; SD=1.2) and being relatively satisfied with the outcomes of the change implemented (M=5.1/7; SD=1.3).

Three themes emerged from the open-ended questions that reflected parents' responses about factors that affected their ability to make changes in how they manage DCD: having access to information with clear recommendations, being supported and finding time, and having the

"right" attitude. Having the right attitude was the most salient aspect, and referred both to parents' attitudes (i.e. developing resilience and patience) and others' attitudes. Others' attitudes appeared particularly important at school, where parents needed to rely on educators' willingness to implement strategies and make accommodations. Most parents reported openness and collaboration with schools; some, however, had negative experiences (e.g., a parent reported that one teacher said she was experienced enough and did not need more information or to be told what to do).

Discussion

This study demonstrated the impact of an online resource in increasing parents' immediate and short-term knowledge and ability to manage DCD. Parents reported having shared evidence-based information with others, trialed strategies, and noticed positive outcomes for the child and family following the intervention. This KT intervention – the evidence-based online module on DCD – is easily accessible. Referring parents to and ensuring that they access evidence-based education could be a way for physicians and health professionals to provide families with the information they need to self-manage this chronic childhood health condition.

Previous studies that piloted the English version of the DCD module reported parental satisfaction and change in knowledge and skills following completion of the website[20,29]. The amount and direction of the changes reported in this study are similar to the ones found in the previous study. The qualitative information provided by this study about behavioral changes and outcomes at three-month follow-up confirms the clinical significance of these changes. The combination of the quantitative and the qualitative findings describe how targeted information (i.e. providing access to an evidence-based website) provided as a stand-alone intervention (i.e. not as part of a broader medical or rehabilitation follow up) can have a significant impact on families' lives. This finding has major implications for the delivery of service to this population. It is important for healthcare professionals, specifically physicians, to be proactive and to refer families to evidence-based websites following a diagnosis. This referral could save time, support the patient-health care professional relationship, and prevent the negative consequences associated with poor quality health information[14,15].

This is the first study to explore the short-term benefits for children with DCD with regards to parental support through provision of web-based information. A few other studies of the use of web-based information with other chronic conditions of childhood were found in a systematic review[21]. Results indicated most interventions involved the provision of direct services through the internet (e.g., monitoring) and evaluated disease-specific outcomes related specifically to the child's condition (e.g., pain). Our findings suggest that the outcomes of using evidence-based websites about childhood chronic conditions might be broader, and could include child and family well-being as shown through participant report of greater self-esteem and satisfaction at both the child and family levels. Website information should address child and family needs, but also target the broader environment to change societal norms, including others' attitudes. Societal norms are an important concept in the Theory of Planned Behavior[23] that might greatly influence parents' intentions and their ability to change behaviors. This is illustrated particularly well in this study by parents' struggle with 'others' attitudes' that might reflect the social norm with regards to typical development and how children are expected to perform motor-related activities at home and at school. Individual and group interventions targeting parents of children with DCD might contribute to changes in their perceptions of these societal norms. However, population-based interventions raising awareness about DCD might be even more effective at changing societal norms and expectations, and ease the implementation of recommended strategies to manage chronic health conditions such as DCD.

Interestingly, when asked about their behavior changes, parents referred to attitudes and beliefs, which in the Theory of Planned Behavior[23] are considered to be separate concepts from behavior changes. Attitudes and behaviors were, however, closely interwoven for participants, which might suggest that, even in the absence of clear behaviors (i.e. tangible actions), we might

improve children's outcomes and prevent secondary consequences by working at the perception levels.

Study limitations and strengths

The use of open, online recruitment strategies and data collection limited our ability to calculate a response rate. Online recruitment is also more sensitive to technological problems – in this study, 22 participants who completed the baseline questionnaire were excluded from the study as the link for the post-intervention questionnaire did not work properly. Online interventions are also known to have a high attrition rate [31,32,33] especially for longer interventions or follow-up data collection[34,35,36]. The 50% attrition rate found in this study was comparable with attrition rates reported for online interventions aiming at changing behaviors[37,38]. Some studies with at-risk populations (e.g., mental health issues) even report attrition rates of 99%[34]. Issues with high attrition rates include decreased studies' power and the risk that the remaining sample is no longer representative of the original sample, possibly affecting the internal and external validity of the study results[39,40]. The statistics used in this study, however, demonstrated there were no differences between the baseline group and the follow up group, and changes in knowledge and skills were still significant when performing a LOCF sensitivity analysis to account for the attrition rate.

The data collection used self-report information and did not control for other events or interventions not related to the website. The questionnaires used were not validated cross-culturally; however, they were based on questionnaires used successfully in other DCD studies.

An important strength of the study is the involvement of our collaborators. The fact there is a DCD parent association in Québec and that rehabilitation centers offer health services to children with DCD imply that DCD is a health condition warranting attention. The integrated KT approach raised awareness among health professionals about the informational needs of families with DCD. The use of the Theory of Planned Behavior[23] to ascertain behavioral changes that occurred following the intervention and after a three-month follow-up provided us with knowledge about how families used the information, and the outcomes and factors influencing their ability to change how they manage DCD. This is a strength of the study given that theoretical grounding and formal evaluation of outcomes are often missing in KT studies[41,42]. Moreover, the study aimed at evaluating an evidence-based online module on DCD; the results might be generalizable to evidence-based modules about other chronic childhood disabilities and can guide KT research in the field of rehabilitation. This study, however, justifies the need for more research using standardized measures to document parents' behavioral changes and children's outcomes.

Conclusion

This study identifies directions for practice, policy and future research in KT and the use of technology to improve health outcomes and the experience of care. Physicians and health professionals should be aware of, and refer their patients to, evidence-based websites that are useful for self-management of disabilities and chronic health conditions, such as DCD, when a diagnosis is given. Planning of services should include provision of information to families, and using evidence-based websites could offer a cost-effective solution. Future research should objectively evaluate the impact of the recommended strategies on children's health outcomes and possible changes to societal norms powered by knowledge sharing.

References

1. Camden C, Wilson B, Kirby A, Sugden D, Missiuna C. Best practice principles for management of children with developmental coordination disorder (DCD): results of a scoping review. *Child Care Health Dev*. 2015;41(1):147-159. doi:10.1111/cch.12128.

2. Missiuna C, Polatajko H, Pollock N. Strategic management of children with developmental coordination disorder. In: *Developmental Coordination Disorder and Its Consequences*. Toronto, ON: University of Toronto Press; 2015.

3. American Psychiatric Association. *Desk Reference to the Diagnostic Criteria From DSM-5®*. American Psychiatric Publishing; 2014.

4. Rivilis I, Hay J, Cairney J, Klentrou P, Liu J, Faught BE. Physical activity and fitness in children with developmental coordination disorder: A systematic review. *Res Dev Disabil*. 2011;32(3):894-910. doi:10.1016/j.ridd.2011.01.017.

5. Cairney J, Hay J, Veldhuizen S, Missiuna C, Mahlberg N, Faught BE. Trajectories of relative weight and waist circumference among children with and without developmental coordination disorder. *Can Med Assoc J*. 2010;182(11):1167-1172. doi:10.1503/cmaj.091454.

6. Engel-Yeger B, Hanna Kasis A. The relationship between Developmental Co-ordination Disorders, child's perceived self-efficacy and preference to participate in daily activities. *Child Care Health Dev*. 2010;36(5):670-677. doi:10.1111/j.1365-2214.2010.01073.x.

7. Stephenson E, Chesson R. "Always the guiding hand": parents' accounts of the long-term implications of developmental co-ordination disorder for their children and families. *Child Care Health Dev*. 2008;34(3):335-343. doi:10.1111/j.1365-2214.2007.00805.x.

8. Dyke P, Buttigieg P, Blackmore A, Ghose A. Use of the Measure of Process of Care for families (MPOC-56) and service providers (MPOC-SP) to evaluate family-centred services in a paediatric disability setting. *Child Care Health Dev*. 2006;32(2):167-176. doi:10.1111/j.1365-2214.2006.00604.x.

9. King G, Cathers T, King S, Rosenbaum P. Major elements of parents' satisfaction and dissatisfaction with pediatric rehabilitation services. *Child Health Care*. 2001;30(2):111-134. doi:10.1207/S15326888CHC3002_3.

10. Missiuna CA, Pollock NA, Levac DE, et al. Partnering for Change: An innovative school-based occupational therapy service delivery model for children with developmental coordination disorder. *Can J Occup Ther*. 2012;79(1):41-50. doi:10.2182/cjot.2012.79.1.6.

11. Camden C. Development and implementation of a new service delivery model for children with disabilities: implications for DCD. *Phys Occup Ther Pediatr*. 2014:1-20.

12. Missiuna C, Moll S, Law M, King S, King G. Mysteries and mazes: Parents' experiences of children with developmental coordination disorder. *Can J Occup Ther*. 2006;73(1):7-17. doi:10.2182/cjot.05.0010.

13. Missiuna C, Gaines R, Soucie H. Why every office needs a tennis ball: a new approach to assessing the clumsy child. *Can Med Assoc J*. 2006;175(5):471-473. doi:10.1503/cmaj.051202.

14. Hesse BW, Nelson DE, Kreps GL, et al. Trust and sources of health information: the impact of the Internet and its implications for health care providers: findings from the first Health Information National Trends Survey. *Arch Intern Med*. 2005;165(22):2618-2624. doi:10.1001/archinte.165.22.2618.

15. Bundorf MK, Wagner TH, Singer SJ, Baker LC. Who searches the internet for health information? *Health Serv Res*. 2006;41(3p1):819-836. doi:10.1111/j.1475-6773.2006.00510.x.

16. Morahan-Martin JM. How internet users find, evaluate, and use online health information: a cross-cultural review. *Cyberpsychol Behav*. 2004;7(5):497-510. doi:10.1089/cpb.2004.7.497.

17. McMullan M. Patients using the Internet to obtain health information: how this affects the patient–health professional relationship. *Patient Educ Couns*. 2006;63(1):24-28. doi:10.1016/j.pec.2005.10.006.

18. Murray E, Lo B, Pollack L, et al. The impact of health information on the internet on the physician-patient relationship: patient perceptions. *Arch Intern Med*. 2003;163(14):1727-1734. doi:10.1001/archinte.163.14.1727.

19. Miyahara M, Butson R, Cutfield R, Clarkson JE. A pilot study of family-focused tele-intervention for children with developmental coordination disorder: development and lessons learned. *Telemed E-Health*. 2009;15(7):707-712. doi:10.1089/tmj.2009.0022.

20. McKechnie X, Embrey X, Pollock N, Missiuna C. *Empowering parents. An online educational workshop on developmental coordination disorder.* Proceedings of the 2012 Canadian Journal of Occupational Therapy conference. 2012.

21. Stinson J, Wilson R, Gill N, Yamada J, Holt J. A systematic review of internet-based self-management interventions for youth with health conditions. *J Pediatr Psychol*. 2009;34(5):495-510. doi:10.1093/jpepsy/jsn115.

22. Graham ID, Logan J, Harrison MB, et al. Lost in knowledge translation: time for a map? *J Contin Educ Health Prof*. 2006;26(1):13-24. doi:10.1002/chp24.

23. Filiatrault J, Richard L. L'apport des théories des changements comportementaux aux interventions de prévention et de promotion de la santé de l'ergothérapeute. *Can J Occup Ther*. 2005;72(1):45-56. doi:10.1177/000841740507200110.

24. Zidarov D, Thomas A, Poissant L. Knowledge translation in physical therapy: from theory to practice. *Disabil Rehabil*. 2013;35(18):1571-1577. doi:10.3109/09638288.2012.748841.

25. Bowen SJ, Graham ID. From knowledge translation to engaged scholarship: Promoting research relevance and utilization. *Arch Phys Med Rehabil*. 2013;94(1):S3-S8. doi:10.1016/j.apmr.2012.04.037.

26. Straus SE, Tetroe J, Graham I. Defining knowledge translation. *Can Med Assoc J*. 2009;181(3-4):165-168. doi:10.1503/cmaj.081229.

27. Colquhoun HL, Brehaut JC, Sales A, et al. A systematic review of the use of theory in randomized controlled trials of audit and feedback. *Implement Sci*. 2013;8(1):66-73. doi:10.1186/1748-5908-8-66.

28. Levac D, Glegg SM, Camden C, Rivard LM, Missiuna C. Best practice recommendations for the development, implementation, and evaluation of online knowledge translation resources in rehabilitation. *Phys Ther*. 2015;95(4):648-662. doi:10.2522/ptj.20130500.

29. Missiuna C, Pollock N, Campbell WN, et al. Use of the Medical Research Council Framework to develop a complex intervention in pediatric occupational therapy: Assessing feasibility. *Res Dev Disabil*. 2012;33(5):1443-1452. doi:10.1016/j.ridd.2012.03.018.

30. Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol*. 2006;3(2):77-101. doi:10.1191/1478088706qp063oa.

31. Kauffman H. A review of predictive factors of student success in and satisfaction with online learning. *Research in Learning Technology*. 2015;*23*. doi: 10.3402/rlt.v23.26507

32. Kelders SM, Kok RN, Ossebaard HC, Van Gemert-Pijnen, J. E. Persuasive system design does matter: a systematic review of adherence to web-based interventions. *J Med Internet Res*. 2012;*14*(6), e152. doi: 10.2196/jmir.2104

33. Eysenbach G. The law of attrition. *J Med Internet Res*.2005;*7*(1), e11. doi: 10.2196/jmir.7.1.e11

34. Farvolden P, Denisoff E, Selby P, Bagby RM, Rudy L. Usage and longitudinal effectiveness of a Web-based self-help cognitive behavioral therapy program for panic disorder. *J Med Internet Res*.2005; *7*(1), e7. doi: 10.2196/jmir.7.1.e7

35. Macea DD, Gajos K, Calil YAD., Fregni F. The efficacy of Web-based cognitive behavioral interventions for chronic pain: a systematic review and meta-analysis. *J Pain*. 2010;*11*(10), 917-929. doi: 10.1016/j.jpain.2010.06.005

36. Harvey-Berino J, Pintauro S, Buzzell P, Gold EC. Effect of internet support on the long-term maintenance of weight loss. *Obesity research*.2004;*12*(2), 320-329. doi: 10.1038/oby.2004.40

37. Springvloet L, Lechner L, de Vries H, Oenema A. Long-term efficacy of a Web-based computer-tailored nutrition education intervention for adults including cognitive and environmental feedback: a randomized controlled trial. *BMC public health*.2015; *15*(1), 1.doi: 10.1186/s12889-015-1707-4

38. Strecher VJ, Shiffman S, West R. Randomized controlled trial of a web-based computer-tailored smoking cessation program as a supplement to nicotine patch therapy. *Addiction*.2005;*100*(5), 682-688. doi: 10.1111/j.1360-0443.2005.01093.x

39. Barry AE. How attrition impacts the internal and external validity of longitudinal research. *The Journal of school health*.2005; *75*(7), 267.

40. Kubitskey BW, Vath RJ, Johnson HJ, Fishman BJ, Konstantopoulos S, Park GJ. Examining study attrition: Implications for experimental research on professional development. *Teaching and Teacher Education*.2012; *28*(3), 418-427. 10.1016/j.tate.2011.11.008

41. Curran VR, Fleet L. A review of evaluation outcomes of web-based continuing medical education. *Med Educ*. 2005;39(6):561-567. doi:10.1111/j.1365-2929.2005.02173.x.

42. Thomas A, Menon A, Boruff J, Rodriguez AM, Ahmed S. Applications of social constructivist learning theories in knowledge translation for healthcare professionals: a scoping review. *Implement Sci*. 2014;9(1):54-74. doi:10.1186/1748-5908-9-54.

Table 1. Demographics of participants who responded to the questionnaires

Demographics characteristics	BASELINE n (valid %) n =116	POST n (valid %) n =81	FOLLOW-UP n (valid %) n =58
Relation to child			
Mother	103 (88.8%)	69 (85.2%)	49 (84.5%)
Father	12 (10.3%)	11 (13.6%)	9 (15.5%)
Other	1 (1%)	1 (1.2%)	0 (0%)
Region			
Eastern Townships	19 (16.4%)	15 (18.5%)	12 (20.7%)
Quebec City	13 (11.2%)	7 (8.6%)	6 (10.3%)
Other regions in Quebec (i.e. outside our partners' territory)	68 (58.6%)	52 (64.2%)	35 (60.3%)
Other regions in Canada, in Europe and elsewhere	16 (13.8%)	7 (8.6%)	5 (8.6%)
Child's age			
0-5 years old	15 (12.9%)	11 (13.6%)	9 (15.5%)
6-12 years old	90 (77.6%)	62 (76.5%)	44 (75.9%)
13-17 years old	5 (4.3%)	3 (3.7%)	3 (5.2%)
18 years old and over	6 (5.2%)	5 (6.2%)	2 (3.4%)
Child's sex			
Boy	86 (74.1%)	58 (71.6%)	41 (70.7%)
Child's having a diagnosis of DCD			
Yes	105 (90.5%)	73 (90.1%)	53 (91.4%)
Other diagnoses and health issues			
Attention deficit disorder with/without hyperactivity	65 (56%)	37 (45.7%)	27 (46.6%)
Learning difficulties	46 (39.7%)	27 (33.3%)	18 (31.0%)
Sensory difficulties	32 (27.6%)	21 (25.9%)	15 (25.9%)
Speech and language difficulties	45 (38.8%)	32 (39.5%)	18 (31.0%)
Behavioural issues	14 (12.1%)	7 (8.6%)	4 (6.9%)
Other (such as migraines and muscular difficulties)	17 (14.7%)	9 (11.1%)	4 (6.9%)
No diagnosis at all	8 (6.9%)	4 (4.9%)	2 (3.4%)
Autism spectrum disorders or Asperger's syndrome	1 (1%)	0 (0%)	0 (0.0%)
Membership			
Québec DCD provincial association (AQED)	38 (32.8%)	29 (35.8%)	21 (36.2%)
Another DCD association	8 (6.9%)	6 (7.4%)	6 (10.3%)
Another parental association	14 (12.1%)	10 (12.3%)	7 (12.1%)
Not a member of any association	66 (56.9%)	43 (53.1%)	29 (50.0%)
Knowledge about DCD association/websites			

Québec DCD provincial association (AQED)	95 (81.9%)	71 (87.7%)	50 (86.2%)
SOS Dyspraxie (i.e. a Québec website about dyspraxia)	75 (64.7%)	52 (64.2%)	37 (63.8%)
CanChild (a Canadian website about childhood disability)	21 (18.1%)	19 (23.5%)	11 (19.0%)
Referred to the module/study by			
My child's clinician	4 (3.4%)	3 (3.7%)	3 (5.2%)
The AQED	50 (43.1%)	39 (48.1%)	27 (46.6%)
Found on the CanChild website	3 (2.6%)	2 (2.5%)	2 (3.4%)
Facebook	36 (31%)	21 (25.9%)	17 (29.3%)
Other (such as word of mouth or through an internet search)	23 (19.8%)	16 (20.0%)	9 (15.5%)

Table 2. Services children and families were receiving at the beginning of the study

Description of services received	BASELINE n (valid %) n = 116	POST n (valid %) n = 81	FOLLOW-UP n (valid %) n = 58
Do you receive health/rehabilitation services or support?*			
Yes	93 (80.2%)	67 (82.7%)	49 (85%)
What organization(s) provide(s) you services and support?**			
Rehabilitation centre	40 (43.0%)	31 (46.3%)	22 (45%)
School	44 (47.3%)	35 (52.2%)	26 (53%)
Private clinic	36 (38.7%)	22 (32.8%)	16 (33%)
Community-based centre	13 (14.0%)	7 (10.4%)	5 (10%)
Other (e.g., hospital)	15 (16.1%)	10 (14.9%)	10 (20%)
What professional(s) provide(s) you services and support?**			
Physical therapist	24 (25.8%)	17 (25.4%)	12 (24%)
Occupational therapist	76 (81.7%)	55 (82.1%)	40 (82%)
Specialized educator	40 (43.0)	33 (49.3%)	28 (57%)
Speech and language therapist	58 (62.4%)	40 (59.7%)	28 (57%)
Social worker	20 (21.5%)	11 (16.4%)	8 (16%)
(Neuro)psychologist	45 (48.4%)	33 (49.3%)	23 (47%)
Other (e.g., nutritionists, child psychiatrists and specialist in psychomotricity)	23 (24.7%)	16 (23.9%)	13 (27%)
Did your child have an individualized service plan(s) in the previous year?*			
Yes	89 (76.7%)	61 (75.3%)	44 (76%)
Where was/were the intervention plan(s) held?***	83 (93.3%)	57 (93.4%	43 (98%)
School	20 (22.5%)	15 (24.6%)	8 (18%)
Rehabilitation centre	6 (6.7%)	5 (8.2%)	3 (7%)
Other (e.g., daycare)			
Were you present at the intervention plan(s)?***	82 (92.1%)	56 (91.8%)	40 (91%)
Yes			

*Valid % were calculated over the entire sample.
**Valid % were calculated over the sub-sample of responders who stated they received health/rehabilitation services or support.
*** Valid % were calculated over the sub-sample of responders who‘s child had an individualised service plan in the previous year.

Table 3. Perceived level of knowledge and skills

SELF-REPORTED DCD KNOWLEDGE AND SKILLS	BASELINE n – 116 (score /7 SD)	IMMEDIATE IMPACT n - 81			SHORT-TERM IMPACT n - 58		
		BASELINE (score /7 SD)	POST (score /7 SD)	CHANGE	BASELINE (score /7 SD)	FOLLOW-UP (score /7 SD)	CHANGE
Recognizing typical characteristics of DCD	5.05 (1.17)	5.07 (1.22)	5.86 (1.08)	+0.79	5.14 (1.28)	5.91 (0.96)	+0.77
Understanding the challenges facing the child	4.72 (1.38)	4.74 (1.39)	5.86 (1.13)	+1.12	4.90 (1.28)	6.02 (1.00)	+1.12
Understanding the impact of DCD on the child's:							
• Ability to accomplish daily tasks at home	5.44 (1.42)	5.45 (1.49)	6.22 (1.19)	+0.77	5.57 (1.46)	6.27 (0.97)	+0.70
• Participation in physical activities at home	5.47 (1.36)	5.46 (1.45)	6.16 (1.20)	+0.70	5.57 (1.40)	6.30 (0.95)	+0.73
• Participation in physical activities at school	5.12 (1.41)	5.08 (1.51)	6.09 (1.33)	+1.01	5.07 (1.56)	6.19 (1.13)	+1.12
• Participation in physical activities in the community	5.19 (1.56)	5.13 (1.63)	6.19 (1.14)	+1.06	5.20 (1.60)	6.22 (1.04)	+1.02
• Ability to accomplish tasks at school	5.38 (1.62)	5.28 (1.66)	6.20 (1.29)	+0.92	5.47 (1.50)	6.39 (0.96)	+0.92
• Self-esteem	5.39 (1.50)	5.47 (1.47)	6.15 (1.31)	+0.68	5.66 (1.35)	6.18 (1.14)	+0.52
TOTAL KNOWLEDGE SCORE	5.21 (1.17)	5.20 (1.23)	6.11 (1.03)	+0.91*	5.33 (1.14)	6.20 (0.84)	+0.87*
Explaining the child's:							
• Specific motor difficulties at home	4.78 (1.50)	4.83 (1.49)	5.75 (1.20)	+0.92	4.84 (1.54)	5.74 (1.35)	+0.90
• Specific motor difficulties at school	4.60 (1.46)	4.77 (1.46)	5.59 (1.29)	+0.82	4.88 (1.35)	5.67 (1.28)	+0.79
• Specific motor difficulties in the community	4.34 (1.50)	4.37 (1.54)	5.51 (1.29)	+1.14	4.47 (1.47)	5.52 (1.33)	+1.05
• Useful strategies at home	4.53 (1.56)	4.58 (1.65)	5.54 (1.29)	+0.92	4.62 (1.69)	5.61 (1.40)	+0.99
• Useful strategies at school	4.25 (1.54)	4.44 (1.57)	5.52 (1.33)	+1.08	4.54 (1.52)	5.34 (1.42)	+0.80
• Useful strategies in the community	4.03 (1.47)	4.09 (1.57)	5.38 (1.36)	+1.29	4.09 (1.58)	5.26 (1.38)	+1.17
Using their current knowledge of DCD to:							
• Respond to the child's needs at home	4.76 (1.39)	4.72 (1.43)	5.77 (1.27)	+1.05	4.79 (1.40)	5.73 (1.00)	+0.94
• Respond to the child's needs at school	4.14 (1.40)	4.22 (1.49)	5.37 (1.35)	+1.15	4.34 (1.33)	5.25 (1.30)	+0.91
• Respond to the child's needs in the community	4.08 (1.33)	4.06 (1.36)	5.31 (1.30)	+1.25	4.10 (1.35)	5.34 (1.24)	+1.24
• Share relevant information in response to a need	4.39 (1.49)	4.43 (1.60)	5.67 (1.29)	+1.24	4.55 (1.50)	5.66 (1.20)	+1.11
• Solve issues when they arise	4.01 (1.39)	3.98 (1.46)	5.40 (1.32)	+1.42	4.02 (1.38)	5.34 (1.16)	+1.32
TOTAL SKILLS SCORE	4.35 (1.21)	4.41 (1.26)	5.53 (1.17)	+1.12*	4.48 (1.22)	5.52 (1.13)	+1.04*

*Significant differences (at p = 0.05). Paired t-tests were only undertaken on knowledge and skills scores, rather than on unique questions.
SD = Standard Deviation

Table 4. Participants' behavior with regards to sharing information (at three months)

Description of the behavior	N (valid percent)
Did you share information with someone? (n=58)	
Yes	48 (83%)
With whom did you share the information? (n=48)	
Child's teacher(s)	30 (63%)
Rehabilitation professional(s)	11 (23%)
Members of their family	35 (73%)
Child's doctor	5 (10%)
Coaches or group leaders	7 (15%)
Other (e.g., friends, colleagues)	15 (31%)
Did you…? (n=58)	
Contact new parents' or DCD associations (yes)	41 (71%)
Participate in new web-based discussions about DCD (yes)	26 (45%)
Visit the *CanChild* website for the first time (yes)	23 (40%)
Read new articles or books about DCD (yes)	29 (50%)
Talk/request meetings to talk to your child's teacher (yes)	25 (43%)
Seek/receive rehabilitation services (yes)	19 (33%)
Seek/receive a medical diagnostic (yes)	11 (19%)
Other significant event (e.g., requested financial aid)	6 (10%)